

**GOVERNOR'S COMMISSION ON COMMUNITY-BASED ALTERNATIVES
FOR INDIVIDUALS WITH DISABILITIES'
HEALTH CARE COMMITTEE MEETING MINUTES
January 20, 2017 – 10:00 AM
Center for Disabilities Studies- Room 132A, Newark**

PRESENT: Dr. Jerry Gallucci, DHSS/Chair; Linda Barnett, League of Women Voters; Linda Brittingham, CCHS (via phone); Timothy Brooks, Parent; Alice Coleman, Smith-Coleman Counseling; Shannon Grace Gahs, Bayada Home Health Care; Phyllis Guinivan, CDS; Laura Hendricks, CMMA Policy (phone); Jae Chul Lee, CDS; Pat Maichle, DDC (phone); Karen McGloughlin, DPH; Heidi Mizell, Autism Delaware; Cory Nourie, Nemours AIDHC; Loretta Sarro, Delaware Deaf and Hard of Hearing; Jo Singles, SCPD Support Staff; and Amber Rivard, Support Staff.

Guest(s): Tabatha Offutt-Powell, DHSS/DPH

CALL TO ORDER:

Dr. Gallucci called the meeting to order at 10:01 am.

APPROVAL OF THE DRAFT MINUTES:

Dr. Gallucci motioned for approval of November minutes. Linda Barnett seconded the motion. The November 18, 2016 minutes were approved as submitted.

ADDITIONS OR DELETIONS TO THE AGENDA

None

BUSINESS

Transition Announcements

Kara Odom Walker will be the new Cabinet Secretary for Department of Health and Social Services (DHSS). Dr. Walker is a family practice physician and had been at the PCORI (Patient-Centered Outcomes Research Institute). Delaware has a PICORI Tier 1 grant that researches opioid use in children and adolescents. Tier 1 is the first grant that a group can apply for to develop research questions after which application can be made for the second and third tiers. The PCORI grant was suggested as a possibility related to what the Committee is currently focusing on. Another suggestion was discussion on Policy Memorandum 70 (Inclusion Policy) that the Committee has been working to implement.

Dr. Gallucci spoke about a focus of the Committee—oral health and dental care for adults and persons with disabilities. Susan Pugliese, DDS, is interested co-chairing this Committee and he will be meeting with her next week. He also would like to invite some new membership from the State and the community.

John McNeal will become the new Director of State Council for Persons with Disabilities (SCPD) and Terri Hancharick will be the new co-chair of the Governor's Commission. Eileen Sparling is no longer the Co-Chair of the Committee since she has taken a position in Maryland with the Department of Health and Mental Hygiene (DHMH). She will still be involved with the

Committee after transitioning to her new position. She will also provide her email and phone number as a point of contact. Discussion around a new co-chair to the Committee led to a discussion of what goals the Committee is striving towards in the near future and what big topics to focus on without the CDS/CDC funding (i.e. Dental care benefits for adults and persons with disabilities).

There will be discussion on the workgroups of the Committee. There is no funding for this Committee to support the workgroups; the Committee will discuss a different approach to keeping the workgroups moving forward.

Public Health Information Systems: Describing the Landscape - Data Standards

Tabatha Offutt-Powell reviewed data standards in the Public Health Information Systems. The Epidemiology, Health Data and Informatics Section will be discussing how it leads the discussion of data within public health information systems, the Division of Public Health (DPH) public health information systems, data standards and the Affordable Care Act (ACA) Standards around collecting different types of demographic variables (i.e. race, ethnicity and disability status). A cultural competency assessment was conducted in 2014 that provided results that linked the data related to disability status and ACA Standards. The next steps that are currently being worked on are how to incorporate those standards into the current DPH information system. DPH collects its information from the public and their mission is to protect and promote the health of all the citizens living in Delaware. The vision of DPH is “healthy people in healthy communities” and is Division of Public Health's mission is to protect and promote the health of all people in Delaware.

Other sections in DPH include Family Health Systems Administration that aligns with the Bureau of Maternal and Child Health, Health Promotion and Disease Prevention activities, Health Systems Protection and Epidemiology, Health Data and Informatics. Infectious Disease Prevention and Control is under the DPH Medical Director's Office. The Epidemiology, Health Data and Informatics Section (EHDIS) develops DPH intervention programs and policies. Decisions about public health interventions, programs, and policies are informed by and developed using timely data that have been translated into usable, meaningful information. After collecting the data, the EHDIS decides how to translate the given information in a way that provides change. Optimizing the use of science, practice, and technology, the Epidemiology, Health Data, and Informatics Section will serve as the coordinating unit within the Division of Public Health to lead, support, and facilitate the compilation and analysis of public health data for the generation of epidemiologic evidence and translation of findings into practical and actionable information for internal and external partners. The Informatics Section has staff that understand the operation of the systems that analyze the data including data analysts and business analysts. Epidemiology provides the science for DPH and translates the data that was analyzed and provides it to the public. There are social determinants of health such as Risk and Protective Factors. Risk factors are conditions or variables associated with a lower likelihood of positive outcomes and a higher likelihood of negative or socially undesirable outcomes. Protective factors have the reverse effect: they enhance the likelihood of positive outcomes and lessen the likelihood of negative consequences from exposure to risk. One of the main goals for EHDIS is to identify opportunities and implement procedures for improving public health data availability, accessibility and usability for internal and external stakeholders.

DPH collects from a variety of different data systems (e.g., electronic medical records, survey data on behavioral risk factors, or tobacco surveys). New data systems are being added to DPH due to what is currently going on (e.g., Zika Virus data and other infectious diseases or death

incidents occurring because of violence). The data systems for social determinants of health are based on environmental or behavioral health, performance outputs, health outcomes including disabilities, health inequities, and use of services linked into all the data standards. The ACA in Section 4302 addresses the standardization of data collection; Section 4302 of the Affordable Care Act contains provisions to strengthen federal data collection efforts by requiring that all national federal data collection efforts collect information on race, ethnicity, sex, primary language, and disability status in surveys such as behavioral health surveys. Specific standards were discussed on ACA standards around the primary demographic data (i.e. race, ethnicity, sex, primary language and disability status). A survey was conducted within DPH and sent to all Section Chiefs that oversee health promotions, disease prevention and health system protection. The purpose of the survey was to ascertain what information in the systems that data is collected on - specific variables including disability status - to determine if each variable met the federal standards, regardless of the funding source. The secondary focus was to create an inventory of systems and tools used by DPH to collect data more efficiently for data system programs and health systems.

DPH contacted the funding source to find out if the system was federally funded or if the data dictionary was available and also how to define the variables by using the data dictionary within the systems. One issue would be whether DPH methods met the ACA standards on how the data is collected. Definition on data collection was broadened to explain how data collection operates.

Disability status questions were included in the surveys to meet the ACA standards that are required. The questions were included to help with understanding the status of the individuals that are taking the survey. Disability status questions have broad categories to capture all of the individuals with different disabilities and some questions are mentioned in behavioral risk factor surveys. A question was raised about if it does not meet federal standards, what the next steps would be to make it ACA standard compliant (i.e. Excel Spreadsheet- Data collection Tool). Costs are linked to modifying the tools needed for meeting the standards leading to other barriers in modifications that impacted data.

The Post-Survey Plan was reviewed by DPH with informatics staff that know more about the system and data elements. Most of the information from the survey was left unwritten. DPH met with staff on the different systems such as electronic medical records to understand a basic summary of what next steps to take based on information collected. Once additional data system attributes are collected, DPH can observe other health topics and see if there is record level or population based summary stratification to the County level. The ACA standards discussed practical and reliable estimates to provide up-to-date data in all the demographic areas. There is no development of an Executive Summary for the information systems in DPH based on its complexity. There was discussion with Eileen Sparling on how many systems were used by DPH and how many systems collected specific information. DPH will observe how to improve one system at a time.

The Cultural Competency Assessment was led by The Natural Center for Cultural Competence within Georgetown University's Center for Child and Human Development. The assessment was conducted in October 2014 and the main purpose was to gauge the extent to which the principles, policies, structures and practices of cultural and linguistic competence are embedded in organizational philosophy and infrastructure that are integrated in core public health functions. After the assessment was completed, people were selected in leading activities to identify assessment areas (i.e., data collection).

Data Collection and Use guidance was recommended to establish policies and procedures to ensure an effective and respective collection of patient and consumer self-reported data on race, ethnicity and preferred language (spoken and written) for communicating health care and other needs. The Data Collection and Use guidance recommends modifying paper and electronic medical records to allow collection of specific variables using standardized categories to ensure data will be easily accessible to clinical staff and confidentiality is maintained. Another recommendation was made to include disability status in categories other than race, ethnicity or preferred language. These suggestions were made to improve and progress the system of data collection. DPH should think about the costs associated with progressing forward and include the recommendations. A suggestion was made to propose a budget to the Joint Finance Committee (JFC). One of the budgets that is proposed by DPH is around funds for electronic medical record systems. DPH will look into the cost of proposing a budget based on interactions with EMR revisions.

DPH focused on the top level strategy map to ensure the application data standards and national code sets are on public health informatics. The Chief of Public Health Informatics is involved with the Strategic Plan. Any new system or modification to any existing public health system will be processed through the Informatics Section to see that the national code systems are consistent with the ACA standards. The goal is to have the policies by mid-February that will be reviewed by a leadership team for feedback. DPH will also include this in the JFC Budget piece about EMR aligning well with the surveys and ACA standards. There will be meetings to assist in data collection systems collecting demographics to meet ACA standards. The data that meets ACA standards are at the federal level based upon population surveys. Progress was made since the previous meeting such as the two policies being finalized and they will be reviewed by the DPH leadership team from around the data pieces in ACA standards. There is a better understanding of the different systems in DPH.

A Committee member asked if there is a group that will work on the other systems that impact overall public health to compare that data within health care systems. Tabatha stated that she does not have control over that area and it would be better to contact a Deputy Director. A discussion was had on the systems in a judicial system connecting and linking data with one another. However, the issue with the DPH systems is that they are not linked and should be worked on. A suggestion was made to develop housing demographics to have a geographic perspective on where you have the most information. Another suggestion was to link surveys involving people with Medicaid to education data on the health care systems with disability status. A Committee member asked about disability questions that are used in a survey. Tabatha stated most of the data was collected using the EMR as a data collection tool. Other questions were asked based on the data collection.

Update on Oral Health Project

Jae Chul provided an update on the Oral Health Project. It is a three year project and the Center for Disabilities Studies (CDS) is currently in Year Two of the project. CDS had conducted two surveys (Dental Care Survey and Dentist Survey). The Dental Care Survey provided CDS with collected data that targeted people with four types of disabilities (cognitive impairment, hearing impairment, visual impairment and physical limitations) and parents of people with disability impairments. Jae Chul briefed the Committee on textured statistical data collected from the Dental Care and Dentist surveys that include income, dental experiences, and services that are provided to people with disabilities, topics important (Dentist Survey), barriers and dental insurance coverage.

A Committee member asked about the income of parents versus the income for people with disabilities. Jae Chul stated that in the Dental Care Survey, parents answered the survey based on their own experience. Parents pay for dental care services out of their own savings for their children. Parents that participated in the survey also had answered the survey for their children that are ages six to forty-nine. About three-hundred and fifty-one participants had participated in the dental survey from the beginning of September 2016 to the end of November 2016. Dentists had also shown interest in receiving training and education for providing respectful care and services with cultural competency. There are two barriers to providing people with disabilities with dental care services (patient behavior and severity of disabilities). Assisting with the barriers will help people with severe disabilities obtain the insurance that will cover the expenses. Discussion was made about educating the public to the link between oral healthcare and health effects and also about what groups will be the main focus of the educational training.

The educational training program will be a one-day training in March 2017 and will discuss, in detail, oral health services. Discussions will take place on who will deliver the training and any volunteers that are willing to provide assistance. A suggestion was made for families of people with disabilities; providing video could be another option.

U.S. Access Board/ Accessible Medical Equipment

The Access Board has new accessibility standards concerning medical diagnostic equipment. More information can be found here: <https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking>.

2017 Meeting Schedule

The Committee agreed to meet quarterly (every 3 months). All the meetings will be held at CDS.

ANNOUNCEMENTS

None

ADJOURNMENT

The meeting adjourned at 12:01 pm.

Respectively submitted,

Amber Rivard
Administrative Specialist

ExecOrder50hcm 11-18-16